

Supporting Families

By Family Voices of North Dakota



Children With Special Health Needs

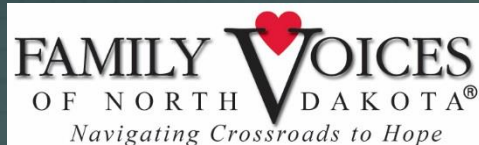
- Are above all children who want to live a happy healthy childhood
- They live in towns, cities and rural areas
- They go to school, church and enjoy community activities

Challenging Conditions

- Some have a physical disability, mental or emotional disabilities
- Others have a chronic health illness

Family Support in ND

- Family Voices is a national grassroots clearinghouse for information and education concerning the health care of our children with special health needs.
- FVND is a state affiliate organization
- We are a Health Information and Education Center for families and professionals, providing information and resources on healthcare, disability and chronic health illnesses and issues affecting children with special health care needs
- There is a Health Information and Education Center in each of the 50 states.



Family Support in ND

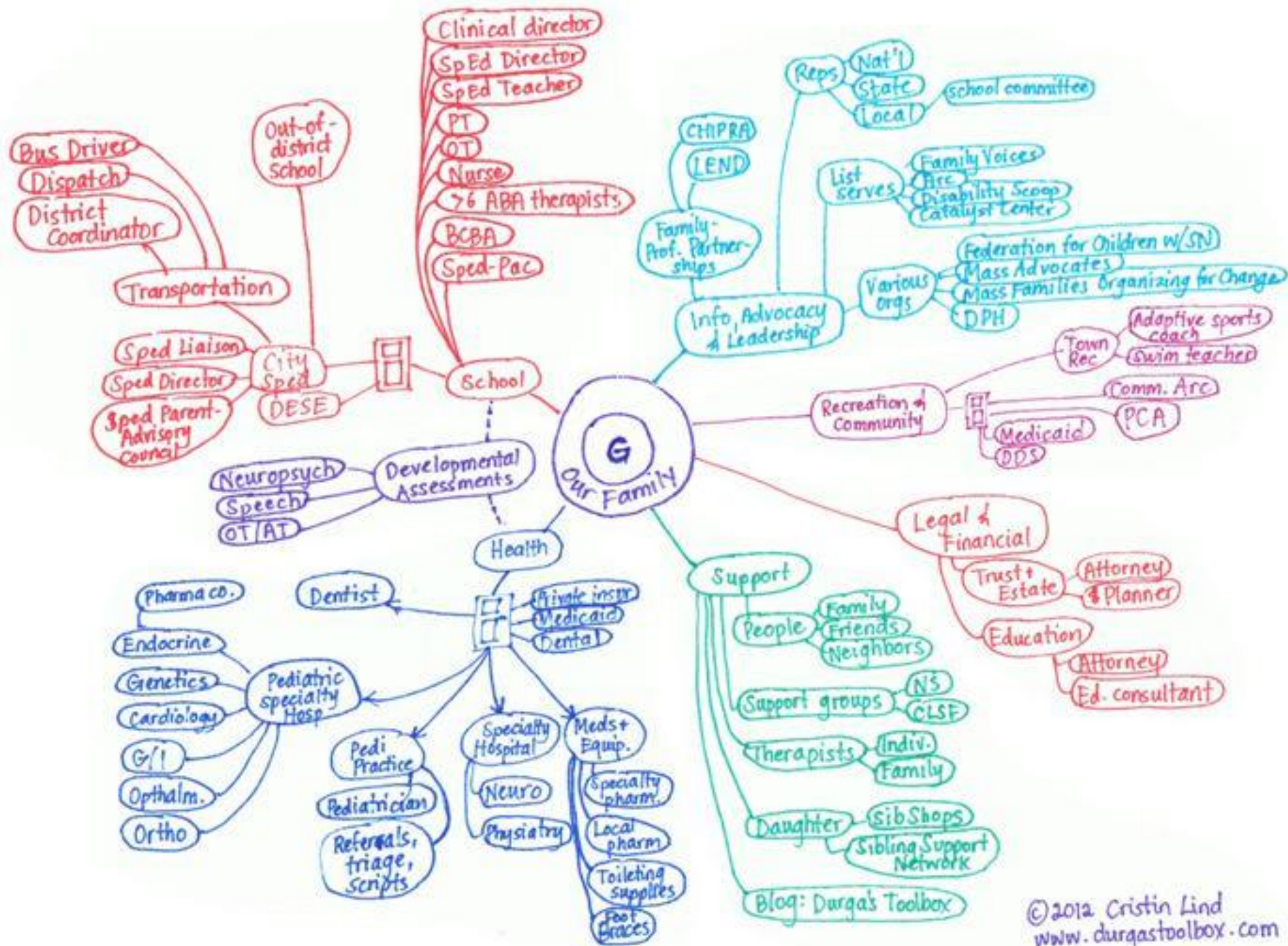
- ND PARENT TO PARENT PROGRAM
- PNT
- In partnership with Designer Genes, Pathfinder Family Center: Project Carson

Project Carson

Family Support in ND

Project Carson:

- Provides parent-to-parent informational and emotional support for families whose baby receives prenatal and just-at-birth diagnosis
- Began because of the stories from families who told about the lack of support in the areas of family support and linkage to community programs
- Covers families across the state of ND.



IN ADDITION TO ALL OF THE PROVIDERS A FAMILY MAY HAVE TO DEAL WITH

There are many additional issues they may be dealing with

FINANCIAL

- ♥ QUALIFYING FOR PROGRAMS
- ♥ CO-PAYS AND PREMIUMS
- ♥ ONE WAGE EARNER
- ♥ SAVINGS????
- ♥ ASSETS
- ♥ FORMS AND MORE FORMS



♥ NO TIME

♥ COMMUNICATION

♥ BLAMING

♥ COPING STRATEGIES AND
ACCEPTANCE DIFFER

♥ CAN MAKE OR BREAK

♥ “The best advise that one of my child’s doctors ever gave me was to make a point to have at least one date night a week with my husband, well that never happened but it was good advice.”

SIBLINGS

- ♥ UNINTENTIONAL NEGLECT
- ♥ HAVE TO GIVE UP “NORM”
- ♥ JEALOUSY
- ♥ ANGER
- ♥ HATE
- ♥ HURT
- ♥ HEALTH
- ♥ EMBARRASEMENT

FAMILY

♥ GRANDPARENTS

♥ DOUBLE GRIEF

♥ OTHER FAMILY MEMBERS

♥ MISUNDERSTAND

♥ “If I can’t even get my family to understand that he has a disability and that it is not bad parenting and my fault, how will anybody else every understand?”

F R I E N D S

♥ INTERESTS BECOME DIFFERENT

♥ GUILT

♥ STOP CALLING

♥ CAN'T UNDERSTAND

♥ DON'T WANT TO HEAR IT
ANYMORE

♥ “I feel guilty because my son is OK and hers isn't. It is hard to call her because I don't know what to say.”

♥ “I call her all the time to go do things but she is always too busy, I finally just

I S O L A T I O N

- ♥ FEEL LIKE YOUR ALL ALONE
- ♥ NO ONE UNDERSTANDS
- ♥ NEED TO FIND NEW MEANING
- ♥ DON'T ENJOY OLD INTERESTS
- ♥ ANNOYED WITH THOSE SEEN AS NORMAL

ROUTINES

♥ CHANGE DRAMATICALLY

♥ MAY NEVER COME BACK

♥ FEEL STUCK

♥ “I feel like it was a successful day when I was able to get out of bed and maybe get a shower.”

VACATIONS

- ♥ ARE SOMETHING THAT DON'T COME BY EASY
 - ♥ BECAUSE OF MONEY
 - ♥ GUILT OF LEAVING
 - ♥ JUST TOO HARD
- ♥ NOT TAKEN FOR GRANTED

STIGMAS

♥ "WELFARE BUM"

♥ TAKE CARE OF OUR OWN

♥ PUBLIC HELP

♥ DISABLED AND SICK SEEN AS BURDENS

♥ UNCOMFORTABLE WITH DIFFERENCES

♥ "It is so hard to apply for something and have the intake worker act as if she is giving me the help out of her own pocket, does she not realize that I work and pay taxes too, we just need a little help to get the services my daughter desperately needs and we cannot afford!"

S P I R I T U A L

- ♥ CAN BECOME MUCH MORE SO
- ♥ CAN WALK AWAY FROM BELIEFS AND COMFORTS
- ♥ CAN FIND NEW MEANING
- ♥ NOT WANTING TO ASK HELP FROM OTHERS

NEW DREAMS

- ♥ PUTTING WHAT ONCE WAS TO REST
- ♥ FINDING HAPPINESS IN NEW WAYS OF LIFE
- ♥ FIND MUCH DEEPER APPRECIATION FOR THINGS OTHERS TAKE FOR GRANTED

NEW RELATIONSHIPS

- ♥ BUILDING FRIENDSHIPS AND SUPPORT AROUND NEW WORLD AND DREAMS
- ♥ PROFESSIONALS BECOME PARTNERS IN OUR CHILDRENS CARE AND FUTURE

JOB

- ♥ NO UNDERSTANDING
- ♥ MORE TIME OFF
- ♥ INSURANCE WORRIES
- ♥ CO-WORKERS
FRUSTRATIONS

REOCCURRING GRIEF

♥ TRANSITIONS

♥ MILESTONES

♥ FOR NO REASON

BURNOUT

- ♥ BECOMES A 24/7 JOB
- ♥ ALL THE RED TAPE
- ♥ ALL THE IGNORANT PEOPLE
- ♥ LACK OF CARE FOR ONE'S SELF
- ♥ FEELINGS OF DEFEAT
- ♥ HAVE TO WORK AT EVERYTHING TO KEEP BALANCE

SACRIFICES

♥ TYPICAL ACTIVITIES

♥ WORLD VIEWS

♥ RELATIONSHIPS

♥ ACTIVITIES

♥ *“FAMILIES WHO RAISE CHILDREN WITH SPECIAL NEEDS OFTEN SACRIFICE THE EASE AND COMFORT MANY PEOPLE BELIEVE LIFE SHOULD BRING THEM, BUT THE DEFINITION OF **SACRIFICE** IS TO **GIVE UP ONE THING** IN EXCHANGE FOR **SOMETHING BETTER.**” FAMILY TIMES*

FAMILIES ARE UNIQUE AND EACH ONE IS A CULTURE OF ITS OWN

♥ FAMILIES WANTS, NEEDS AND
DESIRES ARE DEPENDENT
UPON – *THE INFORMATION,
TRUST, COMPASSION,
RESPECT, EMPOWERMENT AND
SERVICES THEY RECEIVE!*

Family Centered Care

- What is this stuff all about?

Key Elements of FCC

- Recognizing that the family is the constant in the child's life, while the service systems and personnel within those systems fluctuates
- Facilitating parent/professional collaboration at all levels of health care: care of an individual child; program development, implementation, evaluation; and policy formation

- Honoring the racial, ethnic, cultural, and socioeconomic diversity of all families
- Recognizing family strengths and individuality and respecting different methods of coping
- Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information

- Encouraging and facilitating family-to-family support and networking
- Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care systems

- Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families
- Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs.

- Copernicus put the sun rather than the earth at the center of the universe, causing a profound challenge to the conceptualization of the universe
- Similarly, family centered care places the family rather than the service system at the center of the universe

Rud Turnbull, Beach Center



- Families are the primary caregivers and advocates for their children.
- All of the family becomes involved with the coping and caretaking required when they have a child with special health needs.
- A family is at it's best when it meets the family member's needs sufficiently for the family member to grow and develop.

- Children with special health needs bring caregivers and service providers together over longer periods of time
- For this reason it becomes increasingly imperative to work together in a collaborative manner

- In the early 80's health care professionals called for change, recognizing the importance and impact of the family perspective
- Hence, the philosophy of Family Centered Care blossomed and evolved

Family centered care is based on the belief that all families care deeply and want to nurture and support their children

A fundamental element of family centered care is family involvement

****It is a process not a destination**

Families are big, small, extended, nuclear, multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support...A family is a culture unto itself, with different values and unique ways of realizing dreams; together our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states and nations.... Polly Arango

Physicians' and Parents' Ranking of Services

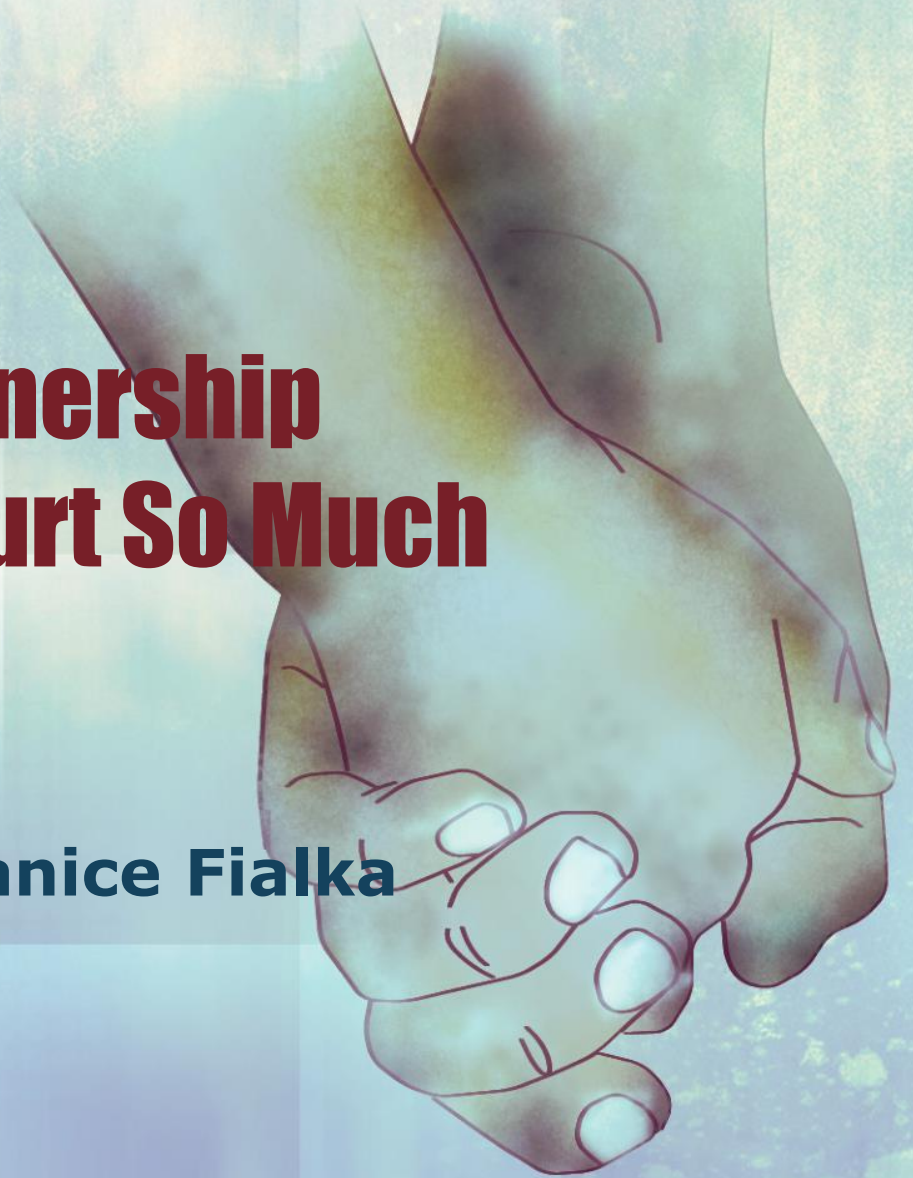
*Ranking

Service	Physicians	Parents
-Respite care	1	9
-Day care	2	21
-Parent support groups	3	3
-Help with behavior problems	4	10
-Financial information or help	5	2
-After-school child care	6	20
-Assistance with physical household changes	7	15
-Vocational counseling	8	6
-Psychological services	9	5
-Homemaker services	10	22
-Recreational opportunities	13	4
-Information about community resources	14	1
-Dental treatment	16	8
-Summer camp	19	7

The Dance of Partnership

Why Do My Feet Hurt So Much

Modeled from Janice Fialka



Building Relationships with Families

Phases I, II & III



Learning a New Dance

- Forming partnerships between families and professionals is like learning a new dance. (Janice Fialka)
- Different expectations: “Mother’s Song.” “Therapist’s Song.” “Special Educator’s Song.” “Paraprofessional’s Song.”

Forming Effective Partnerships

- Requires that partners:
 - Take time to listen to each other's song and try out each other's dance steps.
 - As parents and professionals share their insights, worries, dreams and suggestions and work together, a new, original song is created.

New Choreography

- This sharing opens the “dancers” to a fresh approach and broader perspective of what the child needs.
- Resulting in a new “dance” which reflects the needs of the child and the insights, perspectives and expertise of both families and professionals.

A New Dance

- ▶ This sharing opens the “dancers” to a fresh approach and broader perspective of what the child needs.
- ▶ Resulting in a new “dance” which reflects the needs of the child and the insights, perspectives and expertise of both families and professionals.

Do you want to dance?

- Unspoken Questions:
 - How will you work with me?
 - Will the “dance floor” be rough or smooth
 - If I follow your lead, where will you take me?
 - Will you follow my lead sometimes?
 - What will happen if I step on your toes?
 - Do I have the energy to learn a new dance?

Steps: Collaborative Dance

- Practice, practice, practice
- A process which takes time
 - Conversations and problem-solving strategies assist in building trusting relationships

Colliding/Campaigning

Phase I:

- Unintentionally colliding:
 - Dancing to different music (expectations)
 - Moving in different directions
- Campaigning: (Line Dancing)
 - Promoting the “right approach”
 - Jockey for power, protect territory, etc.

Colliding/Campaigning

Phase I:

- STOP:
 - Compare visions for the child:
 - Find areas of overlap, intervention similarities, explore possibilities.

Initial Perspectives:

- Parents
- Professionals & Paraprofessionals

- “We have had wonderful dreams for our son . . . and I never thought my child might need special education services.”

“Everything is on the line our dreams, our doubts and our fears. Why is our child different? What should we be doing?”

Parents' Voice:

- “We’ve been through so much in the past several years I’m not sure I can handle one more person telling me my child isn’t ‘normal’.”

“I’m scared and, at times, my husband and I feel lost and alone.

Parent's Voice:

- Sometimes, I wish it would all go away so I could go on being my child's mom."

Provider's Voice: Professional/

► “As I welcome you to our school, I am struck by the look on your faces

your child's face beaming with pride as he shows me a new toy, and . . .

your faces are stamped with hope, fear, and grief.”

Providers Voice: Professional/

- “You want us to “fix it,” to give you answers. You deserve answers.”
- “I long to help . . . but often we (professionals & providers) do not have the answers you want to hear.”

Paranormal Professional's Voice:

- “Some parents are angry or withdrawn . . . and some question my expertise. I’m wondering which way you will react to me.”
- “You must be tired of telling your ‘story’ over and over. I will try to be sensitive to that and to your feelings.”

Paraprofessional's Voice: Professional/

- “Sometimes . . . my efforts do not appear to be helpful to you and I feel very alone in this work.”

and Creative Partnering

Phase III: Collaborating

- ▶ Inquiring and listening are cornerstones of success.
- ▶ Comfort levels increase with knowing values are understood and that those involved have a shared view of the child.
- ▶ Partners create a new relationship, new music and dance steps.

Selecting the Rhythm

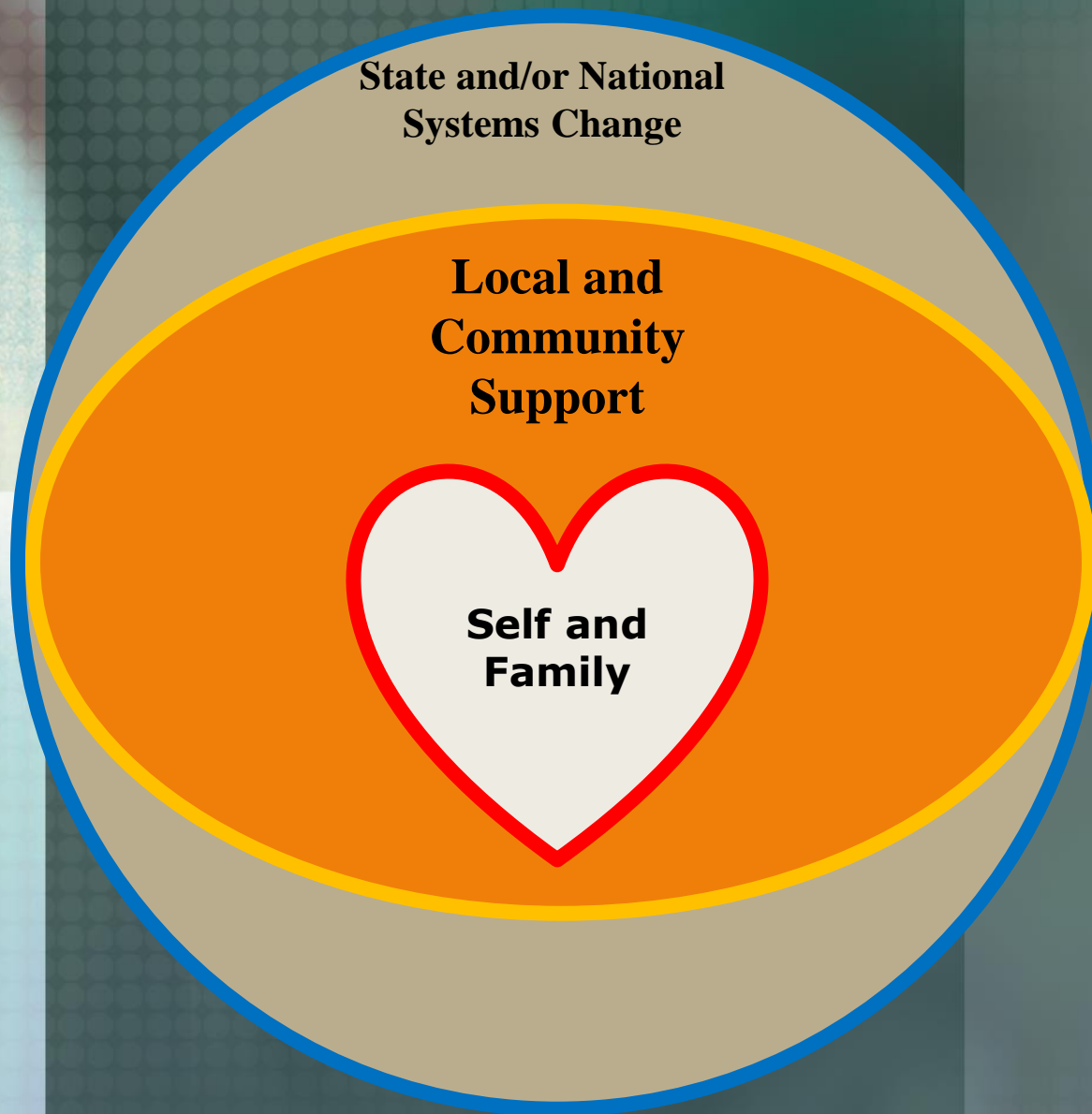
- Circumstances vary the movements.
- If we understand where we are with our partners, we will be able to know better how to move forward.

Changing Partners

- We may not dance gracefully with everyone. And that is OK.

- What families want depends on the difference between the support they already have and what they will need given their situation.

Parent Leadership Growth



From the moment the family walks into a facility, emergency care, or you have a home visit the communication expressed can either make or break the day's encounter

An important step in developing this collaboration is seeking information regarding their preferences, opinions and suggestions about their child's care

Be cautious of
labels such as
noncompliant,
oppositional,
“in denial”,
difficult, over
reactive, or
fragile

- FV National has developed a FCC tool through collaborative partnership with the Maternal and Child Health Bureau

http://www.familyvoices.org/work/family_care

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Designer Genes

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